Organic development of a wellness co-production program for multiple sclerosis:
The Multiple Sclerosis Foundation Wellness Outreach Program

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Disclosures

The presenter and the MSF team have no real or perceived conflicts of interest to report.

Brief videos included with this presentation are shared with the written permission and consent of the participants: Andreanna, Bonnie, Debbie, and Cathy. The MSF program greatly appreciates their willingness to share their comments during this presentation.

Videos are excerpts from a panel discussion by the MSF program team at Concord Hospital in New Hampshire USA in February 2018.
Agenda

• To describe the organic development of the MS peer wellness outreach program

• To discuss health care models which influenced the design of the program and how the program organically developed to fit new models (rather than the other way around)

• To describe the informal co-production network structure and function of the program

• To share experiences of mentors and mentees in the program (videos)

• To welcome related feedback and discussion

Format

• About a third of the session listening to me

• Almost two thirds of the session listening to the mentors and mentees

• Some time at the end for questions and discussion
Multiple Sclerosis

- Chronic progressive neurological disease with no cure
- 2.3 million affected worldwide, 1 million in the United States (NMSS, 2018)
- High comorbidity and disability burden
- Complex coping and management needs
- High cost burden
- Wellness is a critical component
- Access to wellness supports and resources limited, especially in rural areas

Influences of the Initial Program Design

Wagner Chronic Care Model

- Mental Health
- Adherence
- Fatigue
- QoL
Participant Individual Wellness Plans

- Dog Training classes & collar
- Pilates classes
- Personal training
- Swim classes
- Massage therapy
- Yoga classes
- Nutrition classes
- Cooking classes
- General Education Degree (GED) prep course
- Hobby workshops
- Woodworking shop
- Dictation software and software updates (novel writing)
- Fitness club membership
- Power Assist Tricycle
- Cooling Vest (hiking)
- Power Walk Boston
- Music Classes

2017 Participant Feedback (n=16)

- Have you had contact with Peer Mentor?
  - NO CONTACT: 1
  - LESS THAN ONCE A MONTH: 3
  - ONCE A MONTH: 11
  - AT LEAST TWICE A MONTH: 5

- Have you completed an Individual Wellness Plan?
  - YES
  - NO
2017 Participant Feedback (n=16)

How often do you participate in activities from your individual wellness plan?

- I do not remember what my individual wellness plan is: 4
- No participation: 0
- Less than once a month: 0
- Once a month: 2
- Two or more times a month: 14

Do you feel that participating in this program has improved your overall wellness?

- Yes: [CELLRANGE]
- Unsure: [CELLRANGE]
- No: [CELLRANGE]

Profiles: Andreana

- Confronted many of the false stereotypes of living with MS
- Found motivation in helping others develop a “wellness mentality”
- “I know how I felt when I was diagnosed... it is important to me to find newly diagnosed people and give them hope…”
- “It should be about what we can do, not what we can’t.”

Adreanna Moriarty
Peer Mentor

Videos: Andreanna and her mentee, Debbie
Profiles: Bonnie

Wellness Goal:
“Get stronger to improve gait and do exercise to help my muscle pain.”

Wellness Plan: Gym Membership, workouts with peer mentor.

• Strength building
• Stamina building
• Monthly massage

“Shortly after being diagnosed with MS, I was no longer able to do the job I loved. I felt I was not “me” anymore, and felt very depressed. I am so grateful for what this grant has been able to do for me socially, emotionally and physically, helping me to be a better me!”

Bonnie Norton
Current Mentor and Former Mentee

Profiles: Bonnie

“I wanted to find a way to bike again with my friends and family”

Kathy Rouse
Mentee

With guidance from her peer mentor and limited financial assistance from the program, Kathy was able to obtain a power-assist adapted bicycle and return to bicycling.
Kathy bicycling with her grandchildren using her adapted bicycle with power assist...

Left: MSF Wellness Program mentors, mentees present at the New England Regional Meeting of the National Multiple Sclerosis Society in New Hampshire and is featured in a news article in October 2017.

The Union Leader, October, 2017
Success Characteristics

• Low cost (Volunteer driven)
• Mobile resources
• Targets intrinsic motivators, self-efficacy, and peer support
• Sustainability: Mentees become Mentors
• Peer mentors and mentees as leaders, clinician specialist as advisor
• Network meetings: How we found Cathy’s bike...
• Technology helpful but not required

Next Steps

• Formal research of program outcomes
• Replicate
• Scale
• Collaborate
• Technology integration (virtual network capability)
Acknowledgments

Corey Kotz, Peer Mentor

Bonnie Norton, Peer Mentor and former Mentee

Chandlee Adams, BA, MA, former Mentee and Mentor-in-Training

Kathy Rouse, BSN, Mentee

Andreanna Moriarty, Peer Mentor

Debra Boucher, Mentee

Jeffrey Albright, former Mentee

Amy Hall, MS, Project Manager